SUMMARY OF ICASA 2013, Symposium

Disability & HIV in Africa: Leadership, Capacity, Strategies

Muriel Mac-Seing from Handicap International opened the session highlighting that the World Health Organisation (WHO) 2011 World Report on Disability reveals that 15% of the world population (about one billion people) live with one or more disabilities. Hence **universal access and the three zeros: zero infections, zero AIDS-related death and zero discrimination cannot be achieved without including the world largest minority – people with disabilities**.

The first speaker in this session was **Phillimon Simwaba** from the Disability HIV and AIDS Trust (DHAT) a regional Disabled People Organisation (DPO) who focuses on advocacy on the intersection of disability and HIV. Mr. Simwaba highlighted that National Strategic Plans (NSP) in Eastern and Southern Africa do not include or only include rudimentary disability and that an organization like DHAT is involved in advocacy to change this lack of integration. He discussed a number of good practice examples and approaches that DHAT has been using in the past years. For instance DHAT has been advocating on SADAC level influencing the National AIDS Councils NAC. It has also been involved in the development of interventions such as the peer to peer counseling and training of deaf VCT councillors in Zambia. In Rwanda DPOs were involved in the resource mobilization. DPO's in Africa were also involved in the Africa Campaign on disability and HIV, which highlighted the vulnerability of people with disabilities. DPOs have also played a leadership role in the African Union in the process of the minister of health harmonizing health strategies. Most often DPOs use the UNCRPD and its article 25 as well as the UNGASS report. He strongly advocated that **people with disabilities need to be included as a key population. He also emphasized that there are one billion people with disabilities in the world and that this is actually more then there are people living with HIV (PLHIV), yet less attention has been given to disability.** PLHIV are also experiencing disability and this increases the pool of people with disabilities. He also highlighted that there is already a UNAIDS policy and a strategy brief, as well as several comments to disability in the 2011 declaration of the UN high level meeting. **Leadership from DPOs also needs to include research.** For instance DHAT works in collaborations with HEARD and ICDR that provide research expertise and

ensures that people with disabilities are included meaningful in research and have the opportunity to learn from it. DHAT has also formed an alliance with Handicap International and HEARD to promote disability inclusion within the region. However funding is still a major issue and he highlights the need to develop a fund to raise awareness for disability.

The second speaker was **Dr. Toyin Aderemi** from the University of KwaZulu-Natal who is currently conducting her Post-Doc fellowship with HEARD. Dr. Aderemi began her presentation with a quote from the rapporteur session of the XIX International AIDS Conference 2012 by Verderine Hacket: *"universal access, zero infections, zero AIDS-related death and zero discrimination cannot be achieved without including the world largest minority – the disabled".* **Dr Aderemi highlighted that disability and HIV are directly correlated in Eastern and Southern Africa meaning that those countries with the highest HIV prevalence are those that are also having the highest disability prevalence.** She emphasized that this needs thoughts of clarification and research. She provided a summary of research evidence that indicates that a) people with disabilities are at increased risk of exposure to HIV because they are exposed to all known HIV risk factors and are also part of all key populations such as sex workers, MSM and IDUs, b) HIV, its opportunistic infections and the treatment of both may cause impairments and disabilities (including mental health), and c) there may be an viscous cycle of disability, care giving and poverty in the context of HIV that has not been explored as yet. She also highlighted that there are already existing interventions however none of them have been evaluated. She called for the operationalization of this knowledge, more research and more researcher collaboration with implementers on this topic.

Regina Ombam Akoth (NAC Kenya) identified gaps within NSPs. She emphasised that just mentioning the word disability in an NSP is not disability inclusion. She highlights that there is a clear relationship between disability and HIV. Although there is still scientific evidence needed on disability the evidence that exist is enough to provide an argument for actions and to start including disability meaningful in NSPs as well as to implement interventions. She highlighted that we have to address the interrelationship between disability and HIV and look at funding mechanisms, capacity building and addressing stigma and this all needs to start with the NSP. She highlighted there are still misconceptions about disability such as that people with disabilities are not sexual active and cannot be infected with HIV. Hence she advocated to also tackle stigmatization. **She highlighted that although evidence on disability and HIV is recent "we don't need to wait for more evidence to start planning, we can start now, we don't need 101 reports and we need to do this with people with disabilities". D**isability needs to be included in NSPs and this also includes the operationalisation into programming.

Dr Sheila Tlou (UNAIDS) highlighted that people with disabilities are exposed to all known HIV risk factors including sexual violence She shared an example of a school girl in Malawi who was followed and raped by a man in the community. In conversation with Sheila this girl revealed that the perpetrator took advantage of her disability and raped her because she was perceived as an easy victim. Dr Tlou highlighted the importance of the UN Convention on the Rights of Persons with Disabilities (CRPD) and their right to health. **She also emphasised that people**

with disabilities belong to the key populations and that the intersection of disability and HIV has been recognised in the UNAIDS strategy and the 2011 declaration of the UN High Level Meeting HLM. She highlighted the importance of monitoring in regards to disability inclusion, the active inclusion of people with disabilities in structures in the meaning of "Nothing about us without us", the importance of disability inclusion in policies to reinforce human rights but also to ensure sexual and reproductive rights of people with disabilities. She highlighted that so far NSP which include disabilities often only mention some elements of disability inclusion e.g. Braille at the expense of other disability issues (forgetting to include for instance Sign Language or other issues). **She also advocated that disability inclusion needs to go beyond NSPs and also be actively promoted to the County Coordinating Mechanisms (CCM). This includes that UNAIDS needs to stronger advocate disability inclusion with the Global Fund.** She emphasised that more research and evidence is needed to put politicians and policy makers under pressure. She advocated for **the inclusion of disability indicators in the routine data collection on HIV in the same way as we consider sex and age**. She highlighted the need for advocacy and monitoring at country level to ensure that members of the United Nations Family truly 'Deliver as One' on this and other issues as they have been mandated.

Summary and recommendations from the discussion

- Get the evidence from research to influence decision making at national and NSP level, particularly seroprevalence surveys among people with disabilities
- Data disaggregation must consider not only sex and age, but also disability, especially for national-based surveys
- Disabled people's organisations need to be organisationally developed to effectively voice, promote and defend the rights of people with disabilities
- Resources allocation must be prioritized for people with disabilities in HIV policy and programming (HIV prevention, treatment, care and support)
- People with disabilities need to be involved at the Parliament and National AIDS Council levels
- There are enough evidence now to start working towards including the largest minority (one billion people) in to HIV policy and programming through government's commitment
- Include rehabilitation in the context of HIV-related disability to improve quality of life and adherence of those living with HIV

Dr Jill Hanass-Hancock, HEARD